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TITLE: Experiences of Living with Pain after a Spinal Cord Injury

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**CONTRACTING ORGANIZATION:** University of Miami  
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14. ABSTRACT Persistent chronic pain is prevalent after a spinal cord injury (SCI), with about two-thirds of persons with SCI reporting persistent pain despite available treatments. There is a risk for a significant psychosocial impact and a substantially reduced quality of life. The primary goal of the study is to identify barriers and facilitators to coping and management of persistent pain and its impact on activities and participation after SCI. We have successfully completed administrative and other study-related tasks (e.g., database setup, training), and recruited participants consistent with our recruitment goals. The interim analysis has identified 8 overarching areas consistent with our aims and the biopsychosocial perspective of pain (i.e., pain aggravation, coping, self-remedies, experiences/attitudes to treatments & clinical trials, access to pain management, education, social environment, and pain impact). The impact that pain has on an individual's life is determined by a combination of biological factors, including injury and pain types, coping strategies and self-remedies, experiences and attitudes to treatments, access to pain treatment and information, and social environment. We are making progress towards an integrated model for living with SCI and chronic pain that considers the diversity of this population and the perceived barriers and facilitators to successful living.					
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## Table of Contents

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	<u>Page</u>
<b>Introduction</b>	<b>4</b>
<b>Keywords</b>	<b>5</b>
<b>Overall Project Summary</b>	<b>6</b>
<b>Key Research Accomplishments</b>	<b>10</b>
<b>Conclusion</b>	<b>10</b>
<b>Publications, Abstracts, and Presentations</b>	<b>10</b>
<b>Inventions, Patents and Licenses</b>	<b>11</b>
<b>Reportable Outcomes</b>	<b>11</b>
<b>Other Achievements</b>	<b>11</b>
<b>References</b>	<b>11</b>
<b>Appendices</b>	<b>12</b>

## INTRODUCTION:

Persistent chronic pain is prevalent after a spinal cord injury (SCI), with about two-thirds of all persons with SCI reporting persistent pain despite available treatments. Because some of the pain types that occur after a SCI can be both persistent and severe, there is a risk for a significant psychosocial impact and a substantially reduced quality of life. Chronic pain after SCI is associated with lower general health and well-being, and with higher levels of depression. Although pain after SCI has been the topic of multiple basic and clinical research studies, the insufficient management of pain continues to be a significant problem and an important unmet need after SCI. It is clear that in order to treat pain more successfully in this population, we need to increase our understanding of not only the underlying mechanisms of these pain conditions but also how people with SCI manage to live with their pain and what their expectations and experiences are regarding barriers and facilitators to successful pain management and optimal quality of life.

The primary goal of the study is to identify barriers and facilitators to coping and management of persistent pain and its impact on activities and participation after SCI and how this may change with time since injury.

***Specific Aim 1A: To explore the perceptions of individuals with SCI and chronic pain regarding barriers and facilitators for living and coping with pain and SCI.***

***Specific Aim 1B: To explore the perceptions of individuals with SCI and chronic pain regarding barriers and facilitators to activities and participation.***

***Specific Aim 1C: To explore the perceptions of individuals with SCI and chronic pain regarding the barriers and facilitators to pain relief from treatments and self-administered remedies, and the role of social support.***

**KEYWORDS:**

Barriers  
Facilitators  
Multidimensional Pain Inventory  
Neuropathic pain  
Pain Management  
Qualitative semi- structures interview  
Spinal Cord Injury  
The International SCI Pain Basic Dataset

## OVERALL PROJECT SUMMARY:

We have completed with recruitment and broad analysis of thematic themes for Phase 1. These themes have been reviewed by a group of study participants and found to be appropriate. Based on these themes we have designed the Phase 2 survey and these questions have also been reviewed by a group of people with SCI and pain. Recruitment for Phase 2 will start within October, 2014.

The analysis includes factors that make life more difficult (barriers) and easier (facilitators) for those who experience SCI and chronic pain. We have identified several important thematic areas that may either present barriers or facilitators. These include the broad categories access to pain management, coping with pain, educational needs, impact of pain, aggravation of pain, pain characteristics, self-remedies, social environment, and treatments and clinical trials.

We have presented data from this study at national meetings including the American Spinal Injury Association, and American Pain society meetings (see abstracts page 10).

Below is a list of primary barriers and facilitators in regards to access a very important thematic area “pain management”. Please note that the scope of the present study and the data collection is broader (see abstracts page 10) and all major themes are reflected in the attached survey questionnaire.

### Thematic areas for facilitators to pain management include:

- I. Barriers financial insurance
- II. Barriers lack of professional involvement/understanding
- III. Barriers perceived lack of expertise or time
- IV. Barriers poor information and communication
- V. Facilitators clinic type
- VI. Facilitators professional involvement/expertise
- VII. Facilitators understanding your pain & treatments

### **Access to pain management**

This area contains themes related to barriers and facilitators to pain management access. This area includes the following codes (e.g., not using, communication, scheduling and billing, clinic type). One of the common perceptions in this cohort was that their healthcare providers did not understand or deal their pain adequately and that personal engagement from their healthcare provider made a big difference. Below are some examples of quotations representing these areas.

#### **I. Access to pain management: Barriers financial insurance**

*“A big disappointment that’s a really hard part about because I think the doctors don’t prescribe it because the insurance companies give them a hard time with it and even now like doctors don’t prescribe it because like all the stuff that’s coming down, down the line with um you know the illegal um people taking it illegally and, and even. I know down in Homestead like I after the ear surgery, I was, no maybe it was my mom, it was my mom she had surgery on her ankle and on her wrist in one week and she was given Percocet um and we had to go eighteen miles up the road well Wal-mart had it finally but like Wal-greens and them it wasn’t even available, they didn’t even have it down there”.*

*“With the insurance I have now the, they only pay like um with the chiropractic they only pay once a month really you know twelve visits a year and it’s like you know you need more than that especially for me”.*

*“No, like to really and I guess that’s, the, the different things that do work with the pain they don’t you know they don’t cover. Like you said the massage therapy and, and um just the things that work for different, I know that insurance has to cover the general you know they can’t, well that’s better for you so we’ll just cover that for you but it’s like it would be nice if they would cover more of the um more of the things that work for people”.*

*“It’s in a way like an easier fix for them to think about ok well we’ll just give them pills you know like ok and that’s kinda covered but when it comes to things that are not medicines it’s like it just doesn’t seem to be covered and, and for somebody who’s looking at not taking a pill you know well ok what’s my other options you know”.*

*“They still wouldn’t cover a lot of things. It was all oh why don’t you take medication for it, why don’t you take medication for it?”*

*“Well... um... I have a new doctor now. And um, you there’s been a couple of times recently that um, my appointments have cancelled, I didn’t get to see the doctor, Um... on um... well this new doctor I made an appointment on 3, 3 occasions to where I only got to see her once; the other 2 times the appointment was cancelled. And um... I just got the feeling that you know what I’m saying... like you know what I’m saying, the new doctor the understand is not like my old doctor you know”*

*“I tried to tell her about my pain you know, and it was just like... you know I came in she didn’t really feel what I was saying to her “*

*“you will spend a whole day here and by the time you go home you’re in pain and you didn’t get resolved what you needed to get resolved or your halfway through and you’re in the financial aid process and you don’t have this amount of you know information or you made too much money and then you got to pay out of pocket ok well I just paid a weeks’ worth of bills with my paycheck and I can’t pay you right now, oh well then come back”*

*“I feel like it’s great cause I don’t run into any, too many obstacles’, or no problems, the insurance always be right and you get to pick and choose where you want to go at to get treated and so I’m comfortable with the people I been dealing with forever, so. And to be honest I can’t find if I have questions or problems I can’t go nowhere but here or maybe my therapist and them I can ask”*

## **II. Access to pain management: Barriers lack of professional involvement/understanding**

*“This, I guess this is an illusion to them. They, they, I guess they think that okay that’s just, he’s just standing him up”.*

*“When they see me on, on, on the spinal cord ward, they say the same, and my friends when I come back “John you doing good” I’m like, “hmm yeah right”.*

*“I don’t think they deal with it. They just try to write another prescription. That’s what they did”.*

*“The spinal cord doctors just, I don’t, do they deal with pain”?*

*“Well... um... I have a new doctor now. And um, you there’s been a couple of times recently that um, my appointments have cancelled, I didn’t get to see the doctor, Um... on um... well this new doctor I made an*

*appointment on 3, 3 occasions to where I only got to see her once; the other 2 times the appointment was cancelled. And um... I just got the feeling that you know what I'm saying... like you know what I'm saying, the new doctor the understand is not like my old doctor you know".*

*"Well she basically, she basically asked me, she asked me, yeah she gave me some medical care, gave me what I wanted, asked for you know. I need some uh, I needed some more pain medicine and she gave me the prescription, and she gave me some cream but it was just like well what can I help you with and you know I tried to tell her about my pain you know, and it was just like... you know I came in she didn't really feel what I was saying to her".*

*"And then I get here only to find out that the appointment has been cancelled".*

*"I regret like to stop going to the spinal cord clinic you know because again their educated on it and you know they know more about it than a regular primary care physician but again my experience that I told you after Joan retired and then the students are like ok what's wrong ok we'll fix that bye. And the process you have to go through with your finances and everything through the financial office there and the, the people you have to deal with that go there to, like the other patients".*

*"They respond on a, how do you say it, as normal. Uh, what's the word I'm looking for? Routine. As a routine pain. I got a pain in my back they just think oh average pain as far as they ain't gonna think oh it might be related to your spinal cord, your nerves, and its deeper than just exterior pain, you know? And they won't look into it, look into as that. They will just say ok, we gonna give you this, you know, take this patch, you know? Instead of asking real questions as far as how long, or what started it, how I feel and you know? They need to go more in depth".*

*"They don't have time to sit there and say well ok if you take this here this is what's going to happen and this is what going to lead to, this is what going to lead to, they don't have time".*

*"When I'm discussing it with my primary doctor he's not going to be writing papers on my pain um that's not is objective. His objective is to give me a piece of paper that's going to heal it or give me some sort of medication and I'm not one to take medications so he's not the right person to discuss with even though he is a professional that would hear me professionally he's, he wouldn't help in the way that I'm looking for..."*

### **III. Access to pain management: Barriers poor information and communication**

*"They respond on a, how do you say it, as normal. Uh, what's the word I'm looking for? Routine. As a routine pain. I got a pain in my back they just think oh average pain as far as they ain't gonna think oh it might be related to your spinal cord, your nerves, and its deeper than just exterior pain, you know? And they won't look into it, look into as that. They will just say ok, we gonna give you this, you know, take this patch, you know? Instead of asking real questions as far as how long, or what started it, how I feel and you know? They need to go more in depth".*

*"Very little. Maybe with the therapist, some therapist, they've talked to me. And like they not, I don't really wanna say talked but just ask questions, but never really give an answer or opinion. You know, they you know they just ask questions, oh that hurts? Why do you think that hurts? What do you do for that?"*

### **IV. Access to pain management: Facilitator clinic type**

*"I never had surgery and um I was scared you know I prayed a lot and um... I, I, you know, to me it was through, it was through God's grace, because I prayed for the doctors, the technicians anybody affiliated*



*with spinal cord you know, I, you know I, and they did a good job you know I had to thank God and especially they, I found out I had a blood clot and they had to re-open me back up the next day and it didn't move anywhere you know um... I had to thank, you know, I thanked God and I thanked the people involved. You know the VA has been a big help to me in my life".*

*"Pulsating and its uh very debilitating when you have that pain, you can't sleep. Now I have sleep apnea so I'm going through a lot right now with the pain issues. But um the VA's got me uh stable right now so the pain is not as severe".*

**V. Access to pain management: Facilitators professional involvement/expertise**

*"I regret like to stop going to the spinal cord clinic you know because again their educated on it and you know they know more about it than a regular primary care physician but again my experience that I told you after Joan retired and then the students are like ok what's wrong ok we'll fix that bye. And the process you have to go through with your finances and everything through the financial office there and the, the people you have to deal with that go there to, like the other patients".*

*"Yeah, I like him he talk, he actually talk to me and try to find out what's going on".*

*"Better care is if they listen. Listen to the patient, if anyone knows their body more it's the patient".*

*"I feel like it's great cause I don't run into any, too many obstacles', or no problems, the insurance always be right and you get to pick and choose where you want to go at to get treated and so I'm comfortable with the people I been dealing with forever, so. And to be honest I can't find if I have questions or problems I can't go nowhere but here or maybe my therapist Jill and them I can ask".*

*"Yeah, yeah he, he really aware, he don't just take what you say out of your mouth and run with it, he asked you some more questions. Cause, I'm glad though cause you have people abusing their medications and stuff so. And he real strict and he detail oriented, so he can really figure you out if ain't telling the truth, he know, he know better. Cause, come in there talking bout it hurt so bad, no, he gonna ask a couple more questions".*

**VI. Access to pain management: Facilitators understanding your pain & treatments**

*"I've always been interested in that, but I don't know where they do that kind of stuff".*

*"telling them to experiment see what, what causes it to become worse I mean sort of trouble shooting. Asking them questions about their pain might bring out some you know answers to help you tell them maybe what they could do. Find out is there activities that make it worse, what activities help it you know what seems to lessen the pain a little if it is acting up different things like that might help them with the problem solving themselves".*

*"I know my body enough that I can tell, I can differentiate between the different types of pain. How long they have been there, when they're sharp when they're not, when they're this so that I can tell them so they know what to look for".*

### **KEY RESEARCH ACCOMPLISHMENTS:**

- All administrative tasks and logistical study related issues (database setup, training, etc.) have been successful.
- Three abstracts submitted and accepted (see abstracts page 10) presented at major SCI and pain organizations (American Spinal Injury Association, American Pain Society, and the International Association for the Study of Pain).
- Successful recruitment of individuals with SCI and chronic pain for Phase 1.
- Significant amount of data collected regarding pain-related issues of critical importance for individuals with SCI.
- Positive responses from research participants regarding the study (some have never previously been asked about their pain or talked about their pain in depth).
- Broad thematic analysis completed and the themes reviewed by research participants and adapted accordingly.
- Phase 2 study design finalized and survey will be underway during October 2014.

### **CONCLUSION:**

We have identified overarching areas consistent with our aims. Each of these areas includes several themes. The main areas are compatible with a biopsychosocial perspective of pain (i.e. pain aggravation by physical, emotional & other factors, coping with pain, self-remedies to reduce pain, experiences/attitudes to treatments & clinical trials, access to pain management, education of patients, community, healthcare, sources, positive and negative social influences, and pain impact on life, mood, physical activities, sleep, and work.

At present, we suggest that impact of pain determines the experience of living with SCI and chronic pain. The impact of pain is determined by a combination of biological factors, including injury and pain types, demographic factors, and pain-related factors; psychological factors including individual coping strategies and self-remedies and experiences and attitudes regarding treatments and clinical trials; and social factors such as access to treatment and information, and social environment. At the conclusion of this study, we expect to arrive at an integrated model for living with SCI and chronic pain that not only defines critical relationships among domains and barriers and facilitators to successful living, but also considers the immense diversity of this population.

### **PUBLICATIONS, ABSTRACTS, AND PRESENTATIONS:**

#### **Abstracts:**

1. "Patients' perceived Barriers and Facilitators to Pain Management after SCI" results will be presented on October 6- October 11, 2014 at the Scientific Program Committee for the 15<sup>th</sup> World Congress on Pain.
2. "Individual perspectives on coping and self-remedies for persistent pain after SCI" was presented at the American Pain Society meeting been on April 30, 2014 - May 3, 2014.
3. "Clinical sensory pain phenotypes after Spinal Cord Injury" was presented at the American Spinal Injury Association on May 14, 2014 – May 17, 2014.

**Presentations:**

1. “Patients’ perceived Barriers and Facilitators to Pain Management after SCI” results will be presented on October 6 – October 11, 2014 at the Scientific Program Committee for the 15<sup>th</sup> World Congress on Pain.
2. “Individual perspectives on coping and self-remedies for persistent pain after SCI” was presented at the American Pain Society meeting been on April 30, 2014 - May 3, 2014.
3. “Clinical sensory pain phenotypes after Spinal Cord Injury” was presented at the American Spinal Injury Association on May 14, 2014 – May 17, 2014.
4. Analysis of the themes was presented by Dr. Widerstrom-Noga and Dr. Anderson at the Miami Project to cure Paralysis on August 23, 2014 to participants in Phase 1. Major study themes were discussed with phase 1 participants for theme validation. In order to better capture participant’s response the presentation was audio recorded and transcribed.

**INVENTIONS, PATENTS AND LICENSES:**

Nothing to report.

**REPORTABLE OUTCOMES:**

Nothing to report.

**OTHER ACHIEVEMENTS:**

Nothing to report.

**REFERENCES:**

Nothing to report.

#### APPENDICES:

Below is a description of all subjects enrolled in the study in addition to four major components about life interference, affective distress and pain severity.

Demographics for all 35 subjects	
Gender	N
Female	10
Male	25
Veteran Status	
Veterans	6
Non-Veterans	29
Ethnicity	
White Non-Hispanic	15
African American	8
Hispanic	12
Level of Injury	
Paraplegia	15
Tetraplegia	20
ASIA Impairment Scale	
A	17
B	3
C	6
D	9
Type of Pain	
Neuropathic	29
Non-Neuropathic	6
Analgesics & Analgesic Adjuvants	
Anticonvulsant	18
Narcotic/Narcotic-like	16
Antidepressant	8
NSAID	7
None	8

**Multidimensional Pain Inventory- SCI Version.**

<b>MPI-SCI</b>				
<b>No.</b>	<b>Pain Severity</b>	<b>Affective Distress</b>	<b>Life Interference</b>	<b>Category of Pain</b>
	<b>(0-6)</b>	<b>(0-6)</b>	<b>(0-6)</b>	
<b>1</b>	<b>2.33</b>	<b>1.67</b>	<b>2.50</b>	<b>Moderate</b>
<b>2</b>	<b>4.33</b>	<b>3.33</b>	<b>3.88</b>	<b>Severe</b>
<b>3</b>	<b>4.00</b>	<b>4.00</b>	<b>1.63</b>	<b>Severe</b>
<b>4</b>	<b>4.33</b>	<b>1.33</b>	<b>4.38</b>	<b>Severe</b>
<b>5</b>	<b>5.67</b>	<b>3.33</b>	<b>4.13</b>	<b>Severe</b>
<b>6</b>	<b>3.33</b>	<b>3.67</b>	<b>4.13</b>	<b>Moderate</b>
<b>7</b>	<b>4.33</b>	<b>5.67</b>	<b>4.50</b>	<b>Severe</b>
<b>8</b>	<b>3.33</b>	<b>1.33</b>	<b>2.00</b>	<b>Moderate</b>
<b>9</b>	<b>1.00</b>	<b>3.67</b>	<b>1.25</b>	<b>Mild</b>
<b>10</b>	<b>3.00</b>	<b>2.67</b>	<b>1.50</b>	<b>Moderate</b>
<b>11</b>	<b>4.00</b>	<b>5.00</b>	<b>3.38</b>	<b>Severe</b>
<b>12</b>	<b>1.67</b>	<b>1.00</b>	<b>0.00</b>	<b>Mild</b>
<b>13</b>	<b>3.33</b>	<b>2.67</b>	<b>3.88</b>	<b>Moderate</b>
<b>14</b>	<b>2.33</b>	<b>1.00</b>	<b>1.13</b>	<b>Moderate</b>
<b>15</b>	<b>5.00</b>	<b>3.67</b>	<b>2.38</b>	<b>Severe</b>
<b>16</b>	<b>2.67</b>	<b>1.67</b>	<b>1.13</b>	<b>Moderate</b>
<b>17</b>	<b>4.33</b>	<b>4.33</b>	<b>2.13</b>	<b>Severe</b>
<b>18</b>	<b>3.33</b>	<b>3.00</b>	<b>1.50</b>	<b>Moderate</b>
<b>19</b>	<b>3.33</b>	<b>1.67</b>	<b>1.75</b>	<b>Moderate</b>
<b>20</b>	<b>3.00</b>	<b>3.67</b>	<b>2.25</b>	<b>Moderate</b>
<b>21</b>	<b>2.33</b>	<b>1.33</b>	<b>2.25</b>	<b>Moderate</b>
<b>22</b>	<b>3.00</b>	<b>2.67</b>	<b>2.00</b>	<b>Moderate</b>
<b>23</b>	<b>4.00</b>	<b>3.00</b>	<b>3.13</b>	<b>Severe</b>
<b>24</b>	<b>4.67</b>	<b>3.33</b>	<b>3.00</b>	<b>Severe</b>
<b>25</b>	<b>3.33</b>	<b>4.33</b>	<b>4.13</b>	<b>Moderate</b>
<b>26</b>	<b>3.00</b>	<b>2.67</b>	<b>3.13</b>	<b>Moderate</b>
<b>27</b>	<b>2.00</b>	<b>1.67</b>	<b>0.63</b>	<b>Moderate</b>
<b>28</b>	<b>5.33</b>	<b>1.00</b>	<b>2.13</b>	<b>Severe</b>
<b>29</b>	<b>4.00</b>	<b>3.33</b>	<b>3.25</b>	<b>Severe</b>
<b>30</b>	<b>1.67</b>	<b>2.67</b>	<b>0.00</b>	<b>Mild</b>
<b>31</b>	<b>3.67</b>	<b>4.00</b>	<b>2.13</b>	<b>Severe</b>
<b>32</b>	<b>4.00</b>	<b>2.33</b>	<b>4.25</b>	<b>Severe</b>
<b>33</b>	<b>5.33</b>	<b>3.00</b>	<b>5.13</b>	<b>Severe</b>
<b>34</b>	<b>4.67</b>	<b>5.00</b>	<b>4.13</b>	<b>Severe</b>
<b>35</b>	<b>5.00</b>	<b>3.00</b>	<b>3.88</b>	<b>Severe</b>

## ABSTRACTS:

### 1. Abstract will be presented on October 6, 2014- October 11, 2014 at The Scientific Program Committee for the 15th World Congress on Pain.

#### **Patients' perceived barriers and facilitators to pain management after SCI**

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**Aim of Investigation:** Persistent pain after spinal cord injury (SCI) has been investigated in numerous research studies. Despite significantly increased knowledge regarding underlying pain mechanisms, the management of pain continues to be an important unmet need in this population. In order to improve the treatment of pain, it is important to understand individuals' perceptions of important barriers and facilitators to optimal pain management after SCI.

**Methods:** In-depth, qualitative semi-structured interviews with probes were conducted in 29 people (20 males and 9 females) with SCI who experienced persistent pain. The interviews were transcribed verbatim and coded using qualitative analytic software (Atlas.ti). A biopsychosocial *a priori* theoretical framework was used to facilitate thematic coding. The International SCI Pain Basic Dataset and the Multidimensional Pain Inventory (SCI version; MPI-SCI) provided standardized information of pain and psychosocial impact. This data is a subset of a larger study.

**Results:** Ninety-three percent of participants experienced at least 2 simultaneous pain problems, 62% at least 3. Of the 29 persons, 26 (90%) experienced at- or below-level neuropathic pain, 27 (93%) experienced pain daily, and 20 (69%) rated their pain as  $\geq 7$  (0-10 NRS). MPI-SCI mean scores were in the moderate range: Pain Severity ( $3.5 \pm 1.1$ ), Life Interference ( $2.5 \pm 1.2$ ), and Affective Distress ( $2.8 \pm 1.3$ ). Nine people did not use pain medication; others used anticonvulsants (13/29), opioids (12/29), antidepressants (7/29), NSAIDs (5/29), most a combination.

The most frequently reported *barriers* to optimal pain management were related to the patients' perceptions of their health care practitioners (HCPs). These included a perceived lack of professional expertise (related to SCI pain) and/or understanding of their pain problem(s), perceived lack of engagement and/or time, and inadequate information about their pain and treatment options. Barriers related to health insurance or financial factors were less frequently reported. In direct contrast, the most frequently mentioned *facilitators* included the perception of professional engagement and expertise, having access to a clinic and HCPs focusing on SCI and/or pain, and importantly, understanding one's own pain and the treatments that are available.

**Conclusions:** Based on the preliminary results from this study, some people with SCI feel that their HCPs do not have the communication skills, interest or expertise needed to address their pain adequately. However, access to a knowledgeable HCP who communicates well about pain and explores the various treatment options, including the non-pharmacological ones, is perceived as critical for optimal pain management. Another important factor perceived to facilitate pain management is the individual's understanding of their own pain, why they have it, and all available treatment options, enabling a reasonably good interaction with their providers in the short time of typical office visits.

Optimal pain management after SCI is dependent not only on the availability of effective treatments but also on access to knowledgeable HCPs who can communicate information well, or facilitate access to other educational resources, such that their patients become "educated consumers" in their pain management marketplace. The preliminary results suggest that educational efforts for persons with SCI *and* their providers are critical components of *optimal* pain management strategies.

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2. Abstract was presented at the American Pain Society on April 30, 2014 - May 3, 2014.

**Individual perspectives on coping and self-remedies for persistent pain after SCI**

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Although pain after spinal cord injury (SCI) has been the topic of multiple basic and clinical research studies, effective pain management continues to be an important unmet need. In order to better manage pain in this population, we need to increase our knowledge of not only treatment options but also learn from people with SCI how they cope and self-manage pain.

In-depth, semi-structured qualitative interviews were conducted in 21 people (15 males and 6 females) with traumatic SCI who reported persistent pain of at least moderate intensity. The interviews were transcribed and coded using qualitative analytic software. The biopsychosocial model of pain was used to provide *a priori* theoretical framework for the thematic coding. The International SCI Basic Pain Dataset and the Multidimensional Pain Inventory (SCI version; MPI-SCI) were used to collect information regarding pain and psychosocial pain impact. The data presented in this abstract is a subset of a larger study.

All but one participant experienced 2 or 3 different pain types, most experienced neuropathic pain types (19/21) and constant pains (19/21) that were mostly (14/21) rated as severe. The average MPI-SCI scores for all pains were in the moderate range: Pain Severity ( $3.4 \pm 1.2$ ), Life Interference ( $2.5 \pm 1.3$ ), and Affective Distress ( $2.8 \pm 1.4$ ). Six people did not currently use pain medication; others used anticonvulsants (11/21), opioids (9/21), antidepressants (3/21). The most common coping strategies reported to be helpful included resilience/ignoring pain, learning over time/getting used to, distraction, optimism and humor. The most helpful self-remedies used by our participants were exercise/stretching, change of position, massage, thermal and electrical stimulation, meditation and music.

Despite multiple pharmacological treatment options, pain is often severe after SCI. Helpful strategies for coping and self-management learned from people with SCI are important and potentially useful educational components of multidisciplinary pain management.

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3. Abstract was presented at the American Spinal Injury Association on May 14, 2014 – May 17, 2014.  
**Clinical sensory pain phenotypes after Spinal Cord Injury**

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**Objective:** In order to move towards better management of neuropathic pain after spinal cord injury (SCI), an increased mechanistic understanding is needed. The identification of sensory phenotypes is one strategy that potentially can move us closer to mechanisms-based therapies. The purpose of the present study was to define clinical pain phenotypes based upon quantitative sensory testing (QST), and self-reported severity of evoked and spontaneous pain in persons with SCI.

**Design/Method:**

Vibratory, thermal, and pain thresholds were measured in areas below the neurological level of injury in 123 people with SCI and normalized to data obtained from able-bodied control subjects. Pain and demographic data were collected via interview.

**Results:** Cluster analyses of QST, evoked and intensity pain data resulted in three sensory sub-groups: (1) **Severe pain** (NRS 6.9) with minor loss of warm sensation, significant loss of cool and vibratory sensation, and increased thermal pain sensation; (2) **Moderate pain** (Numerical Rating Scale [NRS] 5.9) with significant loss of warm, cool, and vibratory sensation, and minor loss of thermal pain sensation; (3) **Mild pain** (NRS 2.7) with major loss of warm, cool and vibratory sensation, and minor loss of thermal pain sensation. The severe pain group had significantly less deficits in warm and cool sensation, and increased sensitivity to thermal pain compared to the other groups. Neuropathic pain symptom severity including evoked pain was significantly greater in the moderate and severe pain groups compared to the mild pain group.

**Conclusion:** Our results suggest that different clinical sensory pain phenotypes exist after SCI. The relatively low thermal sensitivity, in combination with increased thermal pain sensitivity, in those with severe neuropathic pain, supports the idea that the development of severe pain depend on partial spinothalamic tract damage in combination with inflammatory processes.

**Support:** This project was funded by the Craig Neilsen Foundation #164678.



**SURVEY QUESTIONNAIRE:  
(Phase 2 Web Survey)**

**We wish to know if you have experience pain in the last seven days. Please answer the following questions:**

Have you had any pain during the last seven days including today? ☐ Yes ☐ No

If yes, how many different pain problems do you have?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 or more

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**Please answer the following questions about how pain may interfere with your life. Please select a number ranging from 0 meaning “no interference” to 10 meaning “extreme interference”.**

1. In general, how much has pain interfered with your day-to-day activities in the last week?

No interference  
0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ Extreme interference

2. In general, how much has pain interfered with your overall mood in the last week?

No interference  
0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ Extreme interference

3. In general, how much has pain interfered with your ability to get a good night's sleep in the last week?

No interference  
0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ Extreme interference

**Please answer the following questions about how hard it is for you to deal with your pain. Please select a number ranging from 0 meaning “not hard at all” to 10 meaning “extremely hard”.**

4. Overall, how hard it is for you to deal with your pain?

Not hard at all  
0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ Extremely hard

## Instructions

The following questions are designed to help us learn more about all your pains and how it affects your life. Read each question carefully and then *select a number* on the scale that indicates how that question applies to you.

1. Rate the level of your pain at the present moment.

No pain                      0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    Very intense pain

2. How supportive or helpful is your spouse (significant other) to you in relation to your pain?

Not at all supportive    0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    Extremely supportive

Rate your overall mood during the past week.

Extremely low            0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    Extremely high

3. On the average, how severe has your pain been during the past week?

Not at all severe        0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    Extremely severe

4. How worried is your spouse (or significant other) about you because of your pain?

Not at all worried       0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    Extremely worried

5. During the past week, how much control do you feel that you have over your life?

No control                0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    Extreme control

6. How much suffering do you experience because of your pain?

No suffering              0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    Extreme suffering

7. How attentive is your spouse (significant other) to you because of your pain?

Not at all attentive     0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    Extremely attentive

8. During the past week, how much do you feel that you have been able to deal with your problems?

Not at all                0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    Extremely well

9. How much control do you feel that you have over your pain?

No control at all        0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    A great deal of control

10. During the past week, how irritable have you been?

Not at all irritable      0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    Extremely irritable

11. During the past week, how tense or anxious have you been?

Not at all tense or      0 ☐    1 ☐    2 ☐    3 ☐    4 ☐    5 ☐    6 ☐    Extremely tense or anxious

**Below are some questions that concern factors that may make it easier for you to deal with your pain. Please indicate to what extent you either disagree or agree with the following statements.**

1. I often distract myself with something to help deal with pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
2. When I am in a good mood I often deal better with my pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
3. It has become easier for me to deal with my pain over time  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
4. I often continue on with activities of daily living despite having pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
5. I often continue on social activities despite having pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
6. I often exercise to help relieve/reduce my pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
7. I (or my caregiver) often use massage, heat or electrical stimulation to relieve/reduce my pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
8. I often rest to relieve/reduce my pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
9. I often change position to relieve/reduce my pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
10. I would like my doctor to have good knowledge regarding pain after SCI  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
11. I would like to understand my pain and what treatments are available  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
12. I often use medication to help relieve/reduce my pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
13. I would use a treatment that gives me substantial pain relief even if it has some side effects  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
14. I would use a treatment that only gives me minor pain relief if it has no side effects  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
15. It is easier to deal with my pain when I interact with other people who have an SCI  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
16. It is easier to deal with my pain when I interact with someone who cares about me  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
17. It is easier to deal with my pain when someone helps me with practical things (cleaning, shopping, financial)  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree

18. It is easier to deal with my pain when someone helps me look for information regarding pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree

19. I would like to receive information within the first year after my injury about SCI pain (why it happens,  
available treatments, and ways to self-manage).  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree

20. I would like to receive information about pain throughout the years after my injury about SCI pain (why it  
happens, available treatments, and ways to self-manage).  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree

21. I would like information about multiple treatment options for pain including alternative methods not involving  
medication  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree

**Below are some questions that concern factors that may make it more difficult for you to deal with your pain. Please indicate to what extent you either disagree or agree with the following statements.**

1. One of the most difficult aspects of my pain is that it is so severe  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
2. One of the most difficult aspects of my pain is that it is unpredictable and difficult to understand  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
3. Movement/exercise often makes my pain worse  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
4. Cold temperature often makes my pain worse  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
5. Touch, pressure, other mechanical stimuli, and muscle spasms often make my pain worse  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
6. My pain often decreases my mood  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
7. My pain often limits my participation in social activities  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
8. My pain often limits my participation in physical activities  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
9. My pain often interferes with my sleep  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
10. I do not think that my doctor understands pain after SCI  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
11. I do not think that my doctor spends enough time finding out about my pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
12. I do not think that my doctor gives me enough information or talks to me about my pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
13. I do not think that my insurance covers the types of treatment I would like  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
14. I am less likely to continue using a treatment that causes side effects even if it gives me some pain relief  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
15. I would prefer another treatment than medication  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
16. I am less likely to continue using a treatment that poses a risk for addiction even if it gives me some pain relief  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
17. It is more difficult dealing with my pain when people around me do not understand it  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
18. It is more difficult dealing with my pain when I do not have anyone that I can talk to or who can help  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree

19. I worry about being pitied or creating a burden for other people if I talk about my pain  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree
20. I do not talk about my pain with anyone because they cannot do anything to help me  
I do not agree 0 1 2 3 4 5 6 7 8 9 10 I completely agree

**Below are questions pertaining to Basic Pain Data-Set.**

**First, answer these questions about your WORST pain problem.**

5. Location(s) of your WORST pain (check all areas where your WORST pain problem is located):

- ☐ head
- ☐ neck and/or shoulders
- ☐ arms and/or hands
- ☐ torso (chest, abdomen, pelvis, and/or genitals)
- ☐ back (upper back and/or lower back)
- ☐ hips, buttocks, and/or anus
- ☐ upper legs/thighs
- ☐ lower legs or feet (including knees)

6. Please rate your average pain intensity of your **WORST** pain problem in the past week:

No pain

Pain as bad as you can imagine

0 ☐ 1 ☐ 2 ☐ 3 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐

**Please answer the following questions about how your pain feels to you.**

6a. Is the quality of pain electrical or electric shock like? Yes No

6b. Is the quality of pain like pins and needles, or tingling? Yes No

6c. Does the skin over the area of pain or inside your body where the pain is located feel hot or burning or cold or freezing? Yes No

6d. Does the pain only occur in an area of the body in which you have no feeling on the skin overlying that area? Yes No

7. To the best of your recollection which Year did your **WORST** pain start? \_\_\_\_\_

8. Are you using or receiving any treatment for this pain? Yes No

Now, answer these questions about your **SECOND WORST** pain problem.

9. Location(s) of your **SECOND WORST** pain (check all areas where your **SECOND WORST** pain problem is located):

- ☐ head
- ☐ neck and/or shoulders
- ☐ arms and/or hands
- ☐ torso (chest, abdomen, pelvis, and/or genitals)
- ☐ back (upper back and/or lower back)
- ☐ hips, buttocks, and/or anus
- ☐ upper legs/thighs
- ☐ lower legs or feet (including knees)

10. Average pain intensity of your **SECOND WORST** pain problem in the past week:

No pain

Pain as bad as you can imagine

0 ☐      1 ☐      2 ☐      3 ☐      4 ☐      5 ☐      6 ☐      7 ☐      8 ☐      9 ☐      10 ☐

Please answer the following questions about how your pain feels to you.

10a. Is the quality of pain electrical or electric shock like?    Yes    No

10b. Is the quality of pain like pins and needles, or tingling?    Yes    No

10c. Does the skin over the area of pain or inside your body where the pain is located feel hot or burning or cold or freezing?            Yes    No

10d. Does the pain only occur in an area of the body in which you have no feeling on the skin overlying that area?            Yes    No

11. To the best of your recollection which Year did your **SECOND WORST** pain start? \_\_\_\_\_

12. Are you using or receiving any treatment for this pain?    Yes            No

Now, answer these questions about your **THIRD WORST** pain problem.

13. Location(s) of your **THIRD WORST** pain (check all areas where your **THIRD WORST** pain problem is located):

- ☐ head
- ☐ neck and/or shoulders
- ☐ arms and/or hands
- ☐ torso (chest, abdomen, pelvis, and/or genitals)
- ☐ back (upper back and/or lower back)
- ☐ hips, buttocks, and/or anus
- ☐ upper legs/thighs
- ☐ lower legs or feet (including knees)

14. Average pain intensity of your **THIRD WORST** pain problem in the past week:

No pain

Pain as bad as you can imagine

0 ☐      1 ☐      2 ☐      3 ☐      4 ☐      5 ☐      6 ☐      7 ☐      8 ☐      9 ☐      10 ☐

Please answer the following questions about how your pain feels to you.

14a. Is the quality of pain electrical or electric shock like?    Yes    No

- (End of Survey).*